The lived experience of families living with spinal cord disability in Northeast Thailand

Julie A King and Mark J King

Queensland University of Technology, Australia

Corresponding author:

Dr Julie King is a lecturer in Social Work and Human Services, O Block B Wing Level 6, Kelvin Grove Campus, Queensland University of Technology, Kelvin Grove QLD 4059, Australia. Email: j.macknight-king@qut.edu.au

The Lived Experience of Families Living with Spinal Cord Disability in Northeast Thailand

ABSTRACT *The experience of disability in the global South remains relatively underreported in spite of the greater focus on disability as both an impediment to development and frequently as a result of development. This article reports a qualitative study using ethnographic techniques undertaken in the province of Khon Kaen in Northeast Thailand. The primary participants were men who had experienced a severe spinal cord injury at a time when they were breadwinners, a role which is significant in the context of a modernising state that is an active participant in a global economy. The experiences, constructions and beliefs of these men, their family carers, and other informants illustrate the complex ways in which social and cultural factors interact with the opportunities, challenges and constraints of transition to modernity. The findings, interpreted according to the 'three bodies' approach, illustrate the intersection of colonising effects, governmentality and resistance, and embodied experience in a cultural context.*

Thailand lies in the global South, a country of 67 million[1] of whom an estimated 2.9 per cent are disabled.[2] In the global North, there are several images of Thailand, of which the most dominant is that of a holiday destination that is at the same time both exotic and non-threatening. Alternative images position Thailand either positively as a land of Buddhist monks and elephants, or negatively as a key destination for sex tourism. Further images portray Thailand as a producer of cheap goods (especially brand name rip-offs); a location of political unrest (more recently in Bangkok, and persistently in the Muslim south); a

longstanding ally of the USA adjacent to Indo-Chinese nations which in the past have been less friendly; a staging place for refugees from Burma; a destination for medical tourism; an enchanting backdrop for films; and perhaps still as a victim of the Boxing Day tsunami in 2004.

For Thais themselves, it is a source of pride that Thailand (or Siam), unlike its neighbours, was never colonised in the formal sense, in that it was never governed by a European country or settled by European colonists.[3] In response to the threat perceived from Europe, Thailand set about 'modernising'[4] at all levels, from government and the military down to the individual level.[5] As will be noted later, this process can be construed as a more subtle form of colonisation.

The mix of images of Thailand, as well as its history, demonstrate that Thailand is a country in transition. It exhibits elements of its traditional culture alongside features which indicate ongoing economic development in the service and manufacturing industries, and related social change. In the area of health this has resulted in an epidemiological transition,[6] where industrialisation and increases in motorised travel provide many new opportunities for injury, at the same time as the impact of infectious diseases and child/maternal problems is declining.[7] This paper is about one of the impacts of modernisation – spinal disability through traffic injury. It explores how the lived experience of such a disability is coloured by both Thai culture and social structure, and how it is influenced by elements of the modernisation that can be considered to have contributed to the disabling event in the first place. In doing so, we consider the embodied experience of disability alongside its social and political aspects using the 'three bodies' approach, drawn from the field of medical anthropology.

Baer, Singer and Susser (2003) note that medical anthropology is a relatively young field which is concerned with health in a social and cultural context.[8] The wide variety of methods and theoretical perspectives applied by medical anthropologists is outlined by Brown, Barrett

and Padilla (1998),[9] with one of the important dimensions of difference being between emic and etic approaches.[10] Arthur Kleinman's 'explanatory models' were an early example of the emic approach, which recognised that cultural beliefs may define sickness and health.[11] There are further divisions within medical anthropology, and Sargent and Johnson (1996) describe how critical medical anthropology incorporates social, political and economic factors as important elements of the cultural context of health and illness.[12] The 'three bodies' approach mentioned above (and explained in greater detail later) is a particular perspective in critical medical anthropology which has been expounded most fully by Scheper-Hughes (1994).[13]

Before providing an account of the 'three bodies' approach, the following section presents a concise view of disability in Thailand in terms of the available information.

Disability in Thailand

Given the industrialisation and motorisation described above, it would be reasonable to expect that adult-acquired disability as a result of injury would be a significant problem in Thailand. Unfortunately the available statistics do not paint a very clear picture. As noted above, the most recent data give a population figure for disability of 2.9 per cent in 2007, however earlier surveys report figures that vary between 0.3 per cent and 1.8 per cent.[14] While there is a registration system for people with disabilities in Thailand, it is acknowledged to be well undersubscribed.[15] Consultation of the definitions used in surveys of disability suggests that the wording of the definitions may have something to do with this. For example, the questions in the 1990 census asked 'Is (name) disabled?' and provided the following response categories: Not disabled; Blind; Deaf; Dumb; Armless, legless; Mentally retarded; Insanity; Paralyzed; Others (Specify).[16] The questions were quite specific and (at least in translation) negative in tone. They excluded many disabilities or degrees of disability, for example 'mentally retarded' and 'insanity' were the only cognitive disability categories,

and ‘armless, legless’ and ‘paralyzed’ were the only locomotion disability categories. The restrictive nature of the questions might account for the very low number of disabled people reported in that census (0.3 per cent). It is also likely that, as noted by Kleinman,[17] such supposedly objective statistics are in fact socially and culturally constructed, and the responses that people give to questions are not simply mechanistic reports of physical status. Some credence is loaned to this point of view by disability statistics available online, which give disability prevalence figures that vary from a low of 0.2 per cent of the population, shared by India and Peru in 1981 and Qatar in 1986, through to 39 per cent in rural Norway in 1991.[18] The latter figure is an outlier, but many high income countries report figures of 10 per cent or more. There are large variations within countries over time as well. Low income countries report very low rates, probably due to the use of rather different definitions (constructions) and the possibility of methodological problems in collecting disability data.

Tables of figures, which can be laid side by side, convey an impression of comparability, that we can gain information about disability in Thailand by lining up their figures with those of Norway, or Japan, or Burkina Faso. However, seeing a man with no lower limbs propelling himself through the peak afternoon traffic in Khon Kaen City on a dilapidated wheeled trolley, his fists protected with layers of cloth, suggests that the experience of being disabled in a country like Thailand is too different to be encapsulated in a table. The same reaction is elicited when one visits a village and sees a secondhand wheelchair, donated by a Western organisation, sitting unused in the open living space under a raised house; people sleep upstairs to escape the malarial mosquitoes, it is too hard to carry the injured man up and down the stairs, and there is nowhere to go in a wheelchair anyway – there are no footpaths, when it rains the paths turn to mud, and when it’s dry they’re often rutted and uneven. Clearly the statistics convey very little of this information in a way which contributes to an understanding of life as a person with a disability in Thailand.

Analytical context: the 'three bodies' approach

In a situation like this, where statistics do not provide much information, emic rather than etic research is more likely to be informative and illuminating. The research described here used ethnographic techniques, based on a series of interviews and observations with men in Khon Kaen province in Northeast Thailand who had experienced spinal injury (quadriplegia or paraplegia) as the result of a traffic crash. It is worth noting that involvement in a crash was not a criterion for selection; the intention was to identify men who had been breadwinners, and who had experienced serious spinal disability as the result of a traumatic event. However, in practice all but one of the men had been injured in motorcycle crashes, while the other had been struck by a drunk driver while sitting in a paddy field. In addition to the injured men, their main carers were interviewed in order to gain an insight into the impact of the disability on the family, not just the individual. In Thailand, as in many Asian cultures, collective aims and collective welfare at the level of the family tend to take precedence over individual aims and welfare,[19] yet the response of the family to the disability of a breadwinner in such societies has received little attention.

A central problem in cross-cultural research, addressed in this case through the use of anthropological methods, is to use an approach which takes into account differences in context, language and values. A reflexive approach is typically recommended, taking into account both the researcher's position and the perceptions of participants about the researcher.[20] This extends to the cultural choreographing of personal interactions, where the relative status of interviewer and participant, and social norms about what is appropriate or inappropriate to say, can influence the data. For this reason, verbal information was sought from several sources and discussed with a Thai assistant. Observations were also undertaken,

both of the general situation in which the men lived, and the condition of the men themselves.[21]

Ultimately, however, the focus of the research was on the lived experience of the men and their families, for which the 'three bodies' approach was considered particularly appropriate. Briefly, the 'three bodies' approach posits that each person in a society has three 'bodies': one's own lived experience of a body, the body as a social symbol, and the 'body politic'.[22] Iwakuma (2002), Murphy (1987) and Oliver (2009) stress the embodied experience of a physical disability,[23] and Scheper-Hughes (1994) states that the primary contribution of medical anthropology has been its focus on the body, and the issues of embodiment and corporeality that accompany it.[24] In addition, Oliver argues that the concept of 'having a disability' is not just an individual, physical fact, it has meaning at the social level.[25] Foucault's work illustrates the political aspect of disability, since people with disabilities are defined as a polity which is targeted for health services, employment quotas, and other forms of administrative management.[26] The 'three bodies' approach therefore provides an apt analytical framework with which to conceptualise the participants' experience of disability. It is worth noting that the 'three bodies' approach has begun to be applied more frequently to understanding and interpreting disability, but (as a search reveals) rarely in low or middle income countries.

A consideration of the elements of the 'three bodies' approach shows that it draws on both the interpretive and critical strands of medical anthropology. The 'individual body', and hence the phenomenological experience of disability, reflects the interpretive approach. The 'social body' (the symbolic use of disabled bodies) expresses social and cultural construction, and captures the social values and attitudes called up when seeing (for example) a person in a wheelchair. The arbitration and control functions of the 'body politic' express the critical understanding of disability. In public health it is common for people with disabilities to be

summed up as a set of statistics, classified according to criteria that are supposed to be objective. Their numbers and activities are monitored, and regulatory systems (legislation and programs) are implemented and administered. The argument that these systems of classification and control are socially and culturally constructed has already been noted. Foucault went further, discussing the politically constructed nature of the body and the notion of 'governmentality', a system of controlling bodies through setting norms (which in turn defines deviance), surveillance and regulation.[27] This resonates with critiques of public health approaches both in terms of overall approach and as medically oriented, essentially expressing the values of the global North and dismissive of other cultures,[28] thus lending itself to a critique of the colonising effect of Northern approaches to disability.

The research: Khon Kaen province, Northeast Thailand

Thailand is divided into four large regions – North (includes Chiang Mai), Central (Bangkok and surrounding provinces), South (includes the beach resort areas and Muslim majority provinces) and Northeast. Northeast Thailand is bordered by Laos in the north and Cambodia in the east. It is the poorest region of Thailand[29] and is identified by Thais as Isaan (or Issan), a term which serves multiple purposes as a label for the region, for the people (considered to be more similar to Lao people than to Central Thais) and the dialect. There are 76 provinces in Thailand, of which 20 are in Northeast Thailand, which has about one-third of Thailand's population. The second most populous of the Northeastern provinces is Khon Kaen province, with about 1,700,000 people, and Khon Kaen City (population 380,000) is the provincial capital. The research was conducted with the assistance of Khon Kaen University, Khon Kaen Hospital and Srinakirin Hospital, and the cooperation of staff in health centres in the region. Because both rural and urban experiences were of interest, the main participants (men with spinal injury) were drawn from rural areas (Kok Sri, Ban Wha and Ban Haet in Khon

Kaen province, and Chang Yun in the neighbouring province of Mahasarakham) and Khon Kaen City. It should be noted that the smallest administrative unit is the village, which has broader meaning than in the global North. Even urban areas are subdivided into 'villages' which have their own headman, and one informant referred to his exclusive gated residential community as his village. Khon Kaen City is divided into 17 subdistricts (*tambon*) which are divided into 272 villages (*ban*), while Khon Kaen province has 26 districts (including Khon Kaen City), 198 subdistricts and 2,139 villages.

The qualitative work was conducted by the primary author with the assistance of a translator (a Thai of Chinese ancestry) who had grown up in Khon Kaen. All interviews were taped (with the permission of interviewees) and the primary author worked with the translator to transcribe the tapes into English.[30] As a starting point, in the process of identifying potential participants, several biomedical informants (four doctors, three nurses, a physical therapist, a healthcare worker and a social worker) were interviewed to provide context, and a focus group of eight people from a semi-rural village was conducted in order to identify local terms for various kinds of disabilities, treatments and associated terms, thus assisting the development of interview guides.

With the assistance of Khon Kaen Hospital and Srinakirin Hospital, seven injured men were identified as primary participants and were visited three times at their homes. The first contact involved a brief demographic interview and an introduction to the research and the project, and the second and third contacts were in-depth interviews. At the time of second contact, a primary carer also participated in an in-depth interview. As the research unfolded, the iterative reflexive approach turned up new issues that were followed up. One issue related to medical and transport problems experienced by participants, and was followed up through in-depth interviews with two nurses from primary care units that serviced some of the injured participants. The interviews with the injured men and their carers also highlighted the

importance of Thai Buddhist concepts, earlier animist beliefs common in Northeast Thailand, and the practices of a diverse range of traditional Thai healers. A traditional healer and a Buddhist monk were interviewed about these issues, and earlier information from some biomedical informants was followed up by revisiting them.

Structured observations were undertaken at two hospital rehabilitation units, one occupational unit, on a half-day visit with a community care nurse, at a meeting of the 'Wheelchair Team' at Srinakirin Hospital (men and women in wheelchairs) and at the homes of the injured participants.

Due to constraints on the time (three months) and resources available for the research, and the desire to gain rich qualitative data, the small number of primary participants was inevitable. However, the research ultimately involved 42 interviews with 28 different people, plus a focus group and 26 sets of observations, thereby yielding a substantial volume of transcribed information and descriptions.

The lived experience of injured participants and their families in context

As the research took shape, and the interviews with participants progressed from the first to the second and third, it became clearer that the Thai biomedical informants held views about the beliefs and experiences of the injured men and their families which were at odds with what the men and their families reported, and with what could be observed. The biomedical informants, who had all been trained in biomedical disciplines, presented a view of a modernising Thailand in which the present generation had shrugged off many older cultural beliefs, alongside a romanticised view about what had been retained by Thai society, specifically an altruistic communal spirit. This presents a message in itself: the process of intellectual colonisation (through the embrace of modernisation in education and health) is unsurprisingly uneven, leading to a loss of understanding and connection between an

educated biomedical 'elite' and the people for whose health they bear responsibility. It has been noted that, in most low and middle income countries with stratified societies, the educated elite share more in common with people of similar educational background in countries of the global North than they do with their own compatriots.[31]

A number of themes emerged, and are noted briefly in the following discussion under three broad areas.

The social and cultural construction of risk comprised themes which covered constructions of blame, the role the injured men played as disabled people compared with their former role, expectations of family and community, and experience with community reactions. From the perspective of a highly motorised country, traffic accidents are preventable events which are caused by the behaviour of the road user, a vehicle failure or a problem with the road. An accident victim bears responsibility for their injury if their behaviour directly contributed to the crash. The study participants had a very different construction of causation which meant that they were always to blame, but not necessarily for anything to do with their behaviour immediately before the crash. *Kam* (*karma*) figured largely in their explanations, and some mentioned *phii* (ghosts).

> Investigator: Your accident could have happened to anyone, why do you think it happened to you?
>
> Boonmee[32] (50-year-old quadriplegic, urban location): It was *kam*. I did a lot of bad things and *kam* came.
>
> Investigator: Because you think it was *kam*, do you think there was anything you could have done to prevent the accident?
>
> Boonmee: No, I had *kam* in the past life and this life too. *Kam* made me have the accident because I did not pay respect when I was young where I was supposed to (he did not tell us what he was supposed to pay respect to but it was something sacred). Maybe I did something

> bad with my parents, maybe I cursed or swore at them. Maybe I spoke bad things to my parents, now it is *kam*.

The logic of attribution of blame was a straightforward interpretation of Buddhist cause-and-effect reasoning in the context of reincarnation.[33] Since all events have a cause, a misfortune which occurs to a person when they have done nothing wrong is attributed to that person's offences in a previous life. This interpretation is bolstered by the apparently random nature of road crashes, where risky or illegal behaviour will frequently go unpunished, while innocent people can be killed and injured. References to *phii* draw on traditions which pre-date Buddhism, and involve malevolent spirits (for example, the restless souls of people killed at a particular location in other crashes). This makes them resistant to standard public health messages about prevention.

> In the area that I had the accident there were other accidents, and now the *phii* wait for other people to have an accident and die, and then they can be reborn because they have been replaced. The *phii* find people to replace them to look after the area. This is what people have told me. The area has a lot of accidents. (Mana, 35-year-old paraplegic, rural location)

The same sense of blame for the victim was seen in the how the community's reaction was experienced by the men and their families. The men experienced guilt, which together with a sense of hopelessness contributed to reports of suicidal feelings and suicide attempts. Not only was the victim blamed, but the family experienced a degree of blame by association. This contributed in turn to a view that the responsibility for care resided with the family, not the community. In some cases this meant that men who had been only loosely connected with their family before were now thrust upon them. Within the family itself, a *disability role*

emerged: a helplessness and passivity that the disabled are expected by others to display, and themselves expect to display. This was clear both in observations and in interviews, and was important from a care perspective, since most of the men did not do the rehabilitation exercises which would have helped them, and their carers did not enforce it. The primary author (who has an extensive nursing background) observed pressure sores, evidence of urinary tract infections (UTIs) and other indicators of neglect.

The *way that the household coped with the disability* was a second broad area, covering financial impacts, sources of non-medical support and gaps in support. Whether the injured man had been part of the household before his accident or not, the financial impact of the injury was large, in terms of lost income, treatment and ongoing costs. For most participants this entailed hardship for the foreseeable future. Some men had to be left alone for most of the day while carers worked, simply because there was no other source of income. This included a woman who had to work at a brick factory to support her injured husband and children, another woman who worked to support her injured brother, and a widowed woman who had to work in the rice paddies to support her son. As can be seen, it was not just family, but primarily female members of the family who had to take on the responsibility for care.

> Before the accident I was the head of the house and my family had no problems, but since the accident it is difficult for me and my family, and this includes my parents. Some months we have no money and my wife must go out to work. (Surachai, 37-year-old quadriplegic, rural location)

Further, in some cases wives left their husbands after the injury. A sense of what it meant to be a 'good man' in Isaan emerged – someone who earns money for the family, who can support a wife and children and perhaps his parents. The men who were deserted attributed

the desertion to this loss of role, however it also tied into a broader theme which was observed in the research, on the role of money.

> I have met a lot of these cases and the fibre of love is not there, and they think they will be a burden to them. Their husband cannot look after them, so they go to find someone to look after them and for sex. (Boonmee 50-year-old quadriplegic, urban location)

> First told us he was married and his wife was in Nakhon Pathom, but later admitted that he was separated, only saw his wife once a year, in April, and had been told by a man in the village, who had seen her in Nakhon Pathom, that she had another husband. He told us that this had made him very sad and he had cried. (Notes from demographic interview, Santi, 26-year-old quadriplegic, rural location)

Both the biomedical informants and the primary participants felt that standard of care and wealth were related, a further challenge to the notion of a supportive community. There is evidence that the move towards money as a key element of life in Thailand is relatively recent,[34] and is consistent with a burgeoning impact of globalisation as a form of colonisation.[35] It can be seen that this ostensibly economic form of colonisation has effects on communities and on individual relationships, undercutting prior forms of mutualistic support.

Household coping had a quite physical aspect to it, alluded to earlier. The way that houses are constructed, access to water and power, the roads and paths around houses, all provide challenges and barriers. A strict interpretation of the social model of disability[36] would lay responsibility for this at society's door, as it would assume that disability is determined by an environment which can be changed, given the political will. The group of participants in this study, as paraplegics and quadriplegics, had significant mobility restrictions, so it is hard to imagine the construction of an environment which both removes their disability and is

feasible in today's world, especially in Thailand or in other low and middle income countries.[37] This is somewhat unfair, since the social model was intended by Oliver to be an aid to professional practice rather than a sweeping statement about the social construction of disability.[38] That being said, the Thai environment is extraordinarily unfriendly to paraplegics and quadriplegics. The physical and transport infrastructure make moving around very difficult, even under one's own house. The availability and cost of special transport is prohibitive for households which earn the small amounts of money reported in this study.

> In the rural area they don't have the chance to go to the doctor. The transportation cost is very expensive for the disabled. The bus is 50 baht for a normal person and 1,000 baht for a disabled person.[39] (Doctor at Srinakirin Hospital)

Medical and surveillance-oriented themes characterised the third grouping, specifically *levels of health, interactions with the official system of support, and the use of biomedical and traditional services*. It is perhaps ironic that the steps taken by the Thai government in the area of disability that are recognised as positive by UN ESCAP[40] relate to the degree to which it is increasing its emphasis on surveillance and control devices, such as laws, a registration system and the gathering of statistics, while at the individual level the notional benefits of these devices are often not experienced. Thailand has insufficient resources to provide long term care for the vast majority of quadriplegics and paraplegics. They and their carers are sent home with information on how they can look after themselves and be looked after, however there was evidence that this was not being done effectively, and a suggestion that the disability role contributed to the problem.

Biomedical colonisation of Thai concepts of illness and treatment was being resisted, as evidenced by the use of both traditional and biomedical services. Traditional healers use a variety of techniques, at least some of which appear to draw on traditions which pre-date

Buddhism and probably reflect earlier Hinduism and perhaps animism. One treatment which was mentioned by some, but not experienced by any of the participants in this study, involved being placed on a metal-framed bed among hot coals, while others involved forms of blowing and preparation of poultices.

> They will try every magic, every medicine, anything that they can, and one thing that I will tell them, because it is an ancient belief, is patients that cannot move or cannot feel, you should barbecue them. They put the patient on the fire until they are burn like a feast, like a barbecue, like a chicken, and they come back to the hospital with burns. I always see these patients, so I tell them, I emphasise, "Don't, don't let anybody barbecue you". (Doctor at Srinakirin Hospital)

> One of my relatives went to *maw jup sen*[41] □ it was difficult for him to breathe and walk. The *maw* massaged his legs and now he can walk and breathe. He (the *maw*) can cure a broken nerve in the back and in the neck. (Santi, 26-year-old quadriplegic, rural location)

A wide range of different types of healer were known of, and the cost of treatment was comparable to biomedical treatment costs. Some of the biomedical informants and healthcare worker secondary participants were aware of the use of traditional healers, but others were sure the injured men and their families would not use anything but biomedical services. Only one of the injured men was adamant that traditional healers were ineffective, although he agreed (like other men and their carers) that he was expected by the community to use every avenue which might offer a cure – to the point where all available money was spent. The single greatest impediment to participants in accessing medical services (both biomedical and traditional) was transport, because of the cost. This was a problem because many biomedical

services were only available at hospitals, not healthcare centres, and required regular visits, which in turn was due to a lack of equipment and training at healthcare centres.

Figure 1 provides a conceptual map (one of two)[42] of the relationship between some of the main social, cultural and institutional factors which contributed to the development of a 'disability role' among the men (mentioned above). The map is a simplified representation of what is, in practice, a complex web of interrelated areas which feed back into each other. The arrows with solid lines indicate relationships that were clearly evident in the data, while the arrows with broken lines indicate relationships that are less clear. It is likely that the disability role found here is a sub-element of a more inclusive Thai sick role, although confirmation of this was beyond the scope of this research.

[insert Figure 1]

The 'three bodies'

In accordance with the use of the 'three bodies' approach as an analytical context, the themes and related findings were classified according to their fit with the individual body, the social body and the body politic. Table 1 presents this classification. It should be noted that it refers in places to findings which have not been outlined above because of the need to condense and summarise the extensive material generated.

[insert Table 1]

The 'individual body' refers to the phenomenological experience of being disabled. However, the inclusion of the concept of embodiment adds another dimension to the lived experience of the quadriplegics and paraplegics in this study, emphasising the constant

experience of a maimed body, as expressed in the disability role. The sense of uselessness, and being a burden, in part stems from the increased emphasis in Thai society on money and on capitalist conceptions of humans as being valuable to the extent that they are productive. Transition to modernity has contributed to a hybridity of experience, and this can be seen in the use of both biomedical and traditional healing treatments, also known as sympatricity.[43]

The 'social body' for the disabled in Thailand calls up a range of associations which are not familiar in the global North. The disabled body represents the operation of *kam,* and hence blameworthiness. This justifies stigma and discrimination by the community. There was no sense in this research of any additional social significance associated with the transport-related nature of the injury. This might be different for forms of harm immediately identifiable with particular sources, such as the limb losses experienced as a result of land mines in countries including Cambodia and Afghanistan.

The 'body politic' is the registered disabled person, the subject of legislation and recipient of program benefits. As noted above, it is this Foucauldian sense of surveillance and control which is promoted by international agencies in approaching disability, and it is in this context that the notion of colonisation of disability gains greater relevance. Biomedical approaches are promoted and supported, and while it is easy to find justification for this (evidence-based approaches that are known to work) it has some less desirable consequences. The very people who should understand the life and experiences of Thai people with disabilities are distant from them in terms of beliefs and values, being more similar to their Northern country counterparts than to their Thai compatriots.

Overview and conclusions

In any terms, the impact on a person's life of an injury which results in quadriplegia or paraplegia is immense. In the global North, years of advocacy and reform have brought

public attention to the needs of the disabled. In low/middle income or newly industrialising countries like Thailand, the voices of the disabled are muffled and indistinct. They are caught in a society in transition from rural collectivism to a more urbanised capitalism, made reliant on social institutions which are eroding.

The research reported in this paper took place in rural Northeast Thailand, removing it from the network of Northern and metropolitan power and influence. However, this does not mean that the experiences of disability reported by participants reflect some 'pure' or 'traditional' construction of disability. Thailand was deliberately set on the course of modernisation in the middle of the nineteenth century, using European models to different degrees in different areas of development. This process has continued, and arguably has gained pace in the last few decades.[44] Life for all Thais, therefore, is influenced in one way or another by a globalised economy and its attendant technological and cultural trappings. This was clearly evident at an individual level, when considering the injured participants. All were formerly breadwinners, and had experienced a spinal cord injury. In all cases they had experienced their injury as a result of a traffic crash, even though this was not a criterion for selection. Motorisation, a modernising economy based on capitalism, the desire for consumer goods and the need to earn money were therefore integral parts of their lives, and so their explanations and understandings of their disability (and the explanations and understandings of their families) reflect the modern as well as the traditional.

Reference has been made at several points to colonisation, mainly in the sense that Thailand is being colonised economically through globalisation, that the health system is being colonised by the ideas and practices of biomedicine, and that the elite have had their values and orientation colonised through education. It has been noted that the Thais are proud of never having been colonised, but it has recently and persuasively been argued that, in effect, Thailand has been subject to semicolonisation by the global North, bringing itself into

line in order to avoid the actual fact of full colonisation.[45] A forthcoming paper by Meekosha also argues that there has been colonisation of the concept of disability by the global North.[46] While such metaphorical uses of the concepts of colonisation and postcolonialism are contested,[47] what they have in common is an articulation of the influence of power on individuals, households, organisations, societies, economies and governments. This can be seen in the research reported here, especially in relation to the concepts developed and explored by Foucault. However, we authors must also express a self-conscious awkwardness about the implications of such forms of colonisation, since we are applying the frameworks, conceptualisations and approaches of Northern scholars to the experience of disability in Thailand. This is unavoidable at several levels, one of which is the need to embed research of this kind in an existing academic framework. To the extent that a viable defence can be mounted, we have recourse to the anthropological tradition of ethnography as a way of eliciting the thoughts and experiences of any human being, while acknowledging that we can only report through the lenses of our own understanding.[48]

There is increasing interest in disability in countries of the South, which account for 80 per cent of all people with disabilities. There is a recognition that the social worlds of people in the South differ (sometimes markedly) from those in the global North, which calls for anthropological approaches.[49] We agree with Ingstad in seeking a middle way forward, between the universalism of the biomedical approach to disability, and the particularism inherent in privileging each individual's unique set of constructs.[50] Based on our experience with this research, we are of the view that a critical medical anthropology approach, such as (but not confined to) the 'three bodies' approach, will enable the voices of Southern people with disabilities to be heard.

Notes

[1] CIA World Factbook, accessed at https://www.cia.gov/library/publications/the-world-factbook/geos/th.html, on 20 March 2011.

[2] United Nations Economic and Social Commission for Asia and the Pacific, *Disability at a Glance: a Profile of 36 Countries and Areas in Asia and the Pacific,* Bangkok: UN ESCAP, 2010, p 46.

[3] P A Jackson, 'Autonomy and subordination in Thai history: the case for semicolonial analysis', *Inter-Asia Cultural Studies*, 8(3), 2007, pp 120–134.

[4] We realise that the terms 'modernising', 'modernity' and 'modern' are all problematic; in the Thai context, we are referring to the deliberate replication of European economic, social and value structures commenced in the nineteenth century.

[5] N Mulder, *Inside Thai Society,* Chiang Mai: Silkworm Books, 2000, pp 5–7.

[6] A R Omran, 'The epidemiologic transition. A theory of the epidemiology of population change', *Milbank Memorial Fund Quarterly,* 49(4), 1971, pp 509–538.

[7] World Health Organization, *Global health risks: mortality and burden of disease attributable to selected major risks*, Geneva: WHO, 2009, pp 2–3.

[8] H A Baer, M Singer & I Susser, *Medical Anthropology and the World System,* Westport: Praeger, 2003, p vi.

[9] P J Brown, R L Barrett & M D Padilla, 'Medical anthropology: an introduction to the fields', in P J Brown (ed), *Understanding and Applying Medical Anthropology,* Mountain View: Mayfield, 1998, p 10.

[10] C F Sargent & T M Johnson, 'Introduction', in Sargent & Johnson (eds), *Medical Anthropology: Contemporary Theory and Method,* Westport: Praeger, 1996, p xiii.

[11] A Kleinman, *Patients and Healers in the Context of Culture,* Berkeley: University of California Press, 1980.

[12] Sargent & Johnson.

[13] N Scheper-Hughes, 'Embodied knowledge: thinking with the body in critical medical anthropology', in R Borofsky (ed), *Assessing Cultural Anthropology,* New York: McGraw-Hill, 1994, pp 229-239.

[14] The United Nations website http://unstats.un.org/unsd/demographic/sconcerns/disability/disab2.asp, accessed 24 March 2011, provides links to figures from Thai census statistics for 1986, 1990 and 1991. These cite figures for 'percentage of persons with disability by age and sex', giving figures of 0.7 per cent for 1986, 0.3 per cent for 1990, and 1.4 per cent for 1991. A report by Japan International Cooperation Agency (JICA), *Country Profile on Disability: Kingdom of Thailand*, 2002, provides a comparison of 1991 and 1996 data. The 1991 data give lower figures than the census figures, although they are ostensibly from the same source, and although the

1996 figure is also relatively low (no total is given but it is 1.05 per cent for males and 0.76 per cent for females) JICA estimates that 1.8 per cent of the population has a disability.

[15] JICA (2002) indicates that about 20 per cent of those eligible had registered after the legislation had been in place for nine years.

[16] Questions for the 1991 census only are available at http://unstats.un.org/unsd/demographic/sconcerns/disability/disab2.asp, accessed 24 March 2011.

[17] A Kleinman, *Writing at the Margin,* Berkeley and Los Angeles: University of California Press, 1995.

[18] http://unstats.un.org/unsd/demographic/sconcerns/disability/disab2.asp, accessed 24 March 2011.

[19] The evidence for the role of the family as the unit experiencing disability is drawn from several sources, not all of which will be mentioned here. A Brice and L Campbell, 'Cross-cultural communication', in R L Leavitt (ed), *Cross-Cultural Rehabilitation: An International Perspective,* London: W B Saunders, 1999, pp 83-94 cite Triandis' dimensions of individualism-collectivism and horizontal-vertical social structure in support of the role of family structures in the experience of disability. Research in Africa has demonstrated that the household rather than the individual experiences and deals with the impact of disability or illness: C N Mock, S Gloyd, S Adjei, F Acheampong and O Gish, 'Economic consequences of injury and resulting family coping strategies in Ghana', *Accident Analysis and Prevention,* 35(1), 2003, pp 81□90; R Sauerborn, A Adams and M Hien, 'Household strategies to cope with the economic costs of illness', *Social Science and Medicine,* 43, 1996, pp 291□301; R Sauerborn, A Nougtara, M Hien and H J Diesfeld, 'Seasonal valuations of household costs of illness in Burkina Faso', *Social Science and Medicine,* 43(3), 1996, 281□290.

[20] J Robertson, 'Reflexivity redux: A pithy polemic on "positionality"', *Anthropological Quarterly,* 75(4), 2002, pp 785□792. Robertson briefly outlines the history of reflexivity in anthropology and argues that many anthropologists approach it too rigidly and without acknowledging how participants (as well as researchers) position themselves.

[21] The primary author was a registered nurse with considerable clinical experience, and was able to assess the status of care of the men (bedsores, muscle wastage, care of catheters, etc.) and comment on the disparity between these observations and assertions made about care and rehabilitation.

[22] Scheper-Hughes.

[23] Iwakuma is an anthropologist who describes his own embodied experience of the onset of severe disability: M Iwakuma, 'The body as embodiment: an investigation of the body by Merleau-Ponty', in M Corker and T Shakespeare (eds), *Disability/Postmodernity: Embodying Disability Theory,* London: Continuum, 2002, pp 76-

87. Murphy is another anthropologist who experienced the gradual onset of a severe disability: R F Murphy, *The Body Silent,* New York: Henry Holt, 1987. A similar account of a sudden onset disability is given by M Oliver, *Understanding Disability: From Theory to Practice,* London: Palgrave Macmillan, 2009, pp 13□26.

[24] Scheper-Hughes.

[25] Oliver.

[26] M Foucault, 'Truth and power', in *The Chomsky-Foucault Debate on Human Nature*, New York: The New Press, 2006, pp 140-171.

[27] Foucault, 'Technologies of the self', in L H Martin, H Gutman & P H Hutton (eds), *Technologies of the Self: A Seminar with Michel Foucault,* London: Tavistock Publications, 1988, pp 16-49; Foucault, *Discipline and Punish: The Birth of the Prison,* New York: Vintage Books, 1995; Foucault, 'Omnes et singulatim', in *The Chomsky-Foucault Debate on Human Nature,* New York: The New Press, 2006, pp 172-210; Foucault, 'Truth and power'.

[28] S Nettleton and R Bunton, 'Sociological critiques of health promotion', in R Bunton, S Nettleton & R Burrows (eds), *The Sociology of Health Promotion: Critical Analyses of Consumption, Lifestyle and Risk,* London: Routledge, 1995, pp 41-58; I Wolffers, 'Culture, media, and HIV/AIDS in Asia', *The Lancet,* 349, 1997, pp 52□54.

[29] J A McGregor, L Camfield, A Masae & B Promphakping, 'Development and wellbeing in contemporary Thailand', paper presented at the WeD Conference 2007, Wellbeing in International Development, available at www.welldev.org.uk.

[30] This was an interesting and challenging process in itself, as it became clear that, when there was not a clear correspondence between the Isaan terms and English words, the translator made a judgement as to which English term was closest in meaning. As transcription progressed, and the use of such terms in a range of contexts increased, it sometimes became evident that a different English term would have been more appropriate. The second author reviewed the transcripts and raised questions about translation and meaning that were clarified (where possible) either in discussions with the translator, or in subsequent interviews with the participants.

[31] D Mohan, 'Injury control and safety promotion: ethics, science and practice', in D Mohan and G Tiwari (eds), *Injury Prevention and Control*, London: Taylor and Francis, 2000, pp 1-12.

[32] All names given are pseudonyms.

[33] The influence of Buddhism on the experiences of the participants is not emphasised in the text of this paper, and was probably more pronounced in the actions, rituals and observances of the participants than in what they said. Mulder's description of Thai society provides a useful overview of the role of Buddhism in Thai culture and the implications this has in relationships and interactions, even in the most routine of everyday activities.

[34] S Phongphit and K Hewison, *Village Life: Culture and Transition in Thailand's Northeast.* Bangkok: White Lotus Press, 2001.

[35] M Jackson, 'Globalisation and the colonising state of mind', in M Bargh (ed), *Resistance: An Indigenous Response to Neoliberalism,* Wellington: Huia, 2007, p 181.

[36] Oliver.

[37] C Barnes and G Mercer, *Exploring Disability,* Cambridge: Polity Press, 2011, p 251.

[38] Oliver, pp 10□11. Although Oliver refers to 'a social model' in the singular, other authors consider there to be more than one social model. For example, Shakespeare and Watson refer to Oliver's social model as the 'British social model' and distinguish it from alternative social models which retain the same disability-impairment distinction, but see people with disabilities as one of many minority groups in a political context (T Shakespeare and N Watson, 'The social model of disability: An outdated ideology?', in *Research in Social Science and Disability,* Vol 2, Amsterdam, London: Elsevier, 2001, pp 9-28).

[39] By comparison, at the time a labourer could earn 100 baht per day in the rice fields or as a street cleaner in Bangkok.

[40] UN ESCAP.

[41] *Maw* is a generic term for a traditional healer, usually defined by specialty; a *maw sen* performs massage, while a *maw jup sen* massages nerves, representing a further level of specialisation.

[42] The second conceptual map presented the relationships between factors contributing to sympatric health seeking behaviours. It is not presented both for reasons of brevity and focus, but will be the subject of a later publication.

[43] W Stainton Rogers, *Explaining Health and Illness,* Hemel Hempstead: Harvester Wheatsheaf, 1991.

[44] J Rigg and S Nattapoolwat, 'Embracing the global in Thailand: activism and pragmatism in an era of deagrarianization', *World Development,* 29, 2001, pp 945□960.

[45] Jackson.

[46] H Meekosha, 'Decolonising disability: thinking and acting globally', *Disability and Society*, 26(6), 2011, forthcoming.

[47] M Sherry, '(Post)colonising disability', *Wagadu*, 4(Summer 2007), pp 10-22.

[48] It is worth noting that there are other intellectual traditions which study colonial and postcolonial phenomena, and brief reference was made in this paper to some of the terms which emerge from this discourse, such as the hybridity explored by Bhabha, and the related concepts of transition and liminality. These can be applied to the Thai experience of modernisation in general, and to disability as an example. The first author has explored the application of these concepts in another domain in Thailand and in another setting.

[49] S R Whyte & B Ingstad, 'Introduction: disability connections', in Ingstad & Whyte (eds), *Disability in Local and Global Worlds,* Berkeley and Los Angeles: University of California Press, 2007, pp 1□29.

[50] B Ingstad, 'Seeing disability and human rights in the local context: Botswana revisited', in Ingstad & Whyte (eds), *Disability in Local and Global Worlds,* Berkeley and Los Angeles: University of California Press, 2007, p 253.

Notes on contributors

Julie King (PhD, MPH(TH), BA, RN) is a medical anthropologist who has conducted research into the lived experience of adult-onset physical disability in Thailand and among Indigenous Australians, and has an interest in disability in the global South. She is currently working as an academic in the Faculty of Health at the Queensland University of Technology.

Mark King (PhD, MBA, BScHons) is a member of the Centre for Accident Research and Road Safety – Queensland at the Queensland University of Technology. His research interests include a focus on traffic injury in developing countries and the factors that facilitate or impede successful injury prevention.